

## **Post-Event Summary & Recommendations**



### **Mini-Conference on Health Literacy & Health Disparities**

**Co-Hosted by:  
American Medical Association  
&  
Blue Cross Blue Shield Association**

Northwestern Memorial Hospital Feinberg Pavilion  
251 E. Huron, Chicago, Illinois 60611  
July 21, 2005

**Mini-conference on Health Literacy and Health Disparities**  
**Report Summary and Recommendations**

**Ensuring all patients understand health care information**

Patients have the right to understand healthcare information that is necessary for them to safely care for themselves, and to choose among available alternatives. Health care providers have a duty to provide information in simple, clear, and plain language and to check that the patients have understood the information before ending the conversation.

Currently, the health care system in the United States demands full participation of patients in their own care. While health professionals determine what care is needed, it is up to the patients to provide most of their own care. The instructions for such care are often complex, poorly written, and use unfamiliar concepts appropriate for medical textbooks and not easily understood by patients. While the average American reads at the 8<sup>th</sup> grade level, medical information is usually written at the college level. This puts 50% of the adult population at risk for misunderstandings, medical errors, excess hospitalizations and poorer health outcomes. Research has found that patients with limited literacy skills are twice as likely to be hospitalized and stay in the hospital longer. The excess annual costs to the health care system have been estimated to range from \$50-73 billion.

This situation is most serious for the elderly, many of whom have to cope with problems such as loss of vision and hearing, loss of family support and social isolation, fatigue, pain, chronic illness and cognitive decline, in addition to the multiple instructions for care of multiple illnesses and medications. Seniors, ages 65 and older, account for 40% of all medication use and the average 65 year old has nearly 31 prescriptions filled per year. All medications have the potential of causing harm as well as benefit, the incidence of adverse medication events increases with the number of medications. Medication errors are the most common medical mistakes – some as a result of misread or misunderstood prescription labels – causing up to 7,000 deaths each year and costing the health care system nearly \$77 billion annually. Improving communications on medications can improve care, reduce errors, and save lives.

The decline in social support compounded by chronic illness also makes this population increasingly vulnerable to fraud.

The unrealistic expectations of health care providers that brief oral instructions and lengthy written materials will be sufficient to educate their patients in carrying out unknown and complex self-care tasks pose serious (and unnecessary) safety risks. Low literacy skills affect not only a patient's ability to safely and successfully navigate the many layers within the health care system, but even their ability to gain access to the health care system at all.

While a majority of the 90 million Americans who have inadequate literacy skills are native-born, white and educated in American schools, there are increasing numbers of recent immigrants who need to access the health care system before they become proficient in English. They face almost insurmountable challenges in receiving health care from providers who cannot communicate with them. One recent study found that when family members or untrained interpreters are used to assist with communication, an average of 31 translation errors per visit are made.

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Repeated research studies have found that both these populations – those with inadequate literacy and those with limited English proficiency – experience unexpectedly poor health outcomes, excess hospitalizations, longer lengths of stay in hospital and emergency rooms, and higher costs of care.

**Proposed Solutions:**

- Training in communication strategies (to include giving clear instructions and assessing patient understanding) should be implemented for all health care staff (professional and administrative) to ensure that all patients can accurately summarize the information they need in their own words and demonstrate how the information can be applied in their daily life.
- Public health messages and community outreach should use simple, clear, plain language.
  - Messages should be field-tested with consumers for accuracy and understandability.
  - Special attention should be paid to multicultural media such as radio, local newspapers, community and faith-based organizations.
  - Work with social service agencies, libraries, adult education and local literacy programs.
- Third party payors (Medicare, Medicare + Choice, VA, DOD, Tricare, etc) should make all health information they provide available in simple, clear, plain language (field tested by consumers with limited literacy and limited English proficiency).
- Payment should be provided for the necessary one-on one patient education, as well as other services, to ensure patients understand information provided to them and are able to safely care for themselves. (Other services may include: interpreters, group education sessions, telephone education follow-up, home health care, disease management or chronic care coordination/management programs).
- Simplifying and standardizing written and oral communications to improve patient understanding, to improve patient safety and to reduce medication misuse.
  - All U.S. prescription drug labels should be standardized. Congress should establish a public-private expert panel to develop the uniform format (similar to nutrition labels) which should be validated by consumer focus groups (including consumers with limited literacy and limited English proficiency). Accurate translations in multiple languages should be available for all retail pharmacies to use as needed. Make side-by-side translations available.
  - Standardize basic patient medication information leaflets. Pharmaceutical companies should submit simple, accurate information for consumers about the drug at the time that the FDA is considering approval (this is the procedure in Europe). The patient leaflets should be translated under supervision of the pharmaceutical companies and reviewed by an FDA panel that includes practicing physicians, to ensure the accuracy, fair balance and clinical

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appropriateness of the information. Consumer focus groups should validate the leaflets for the ease of understanding the information.

- Congress should establish a public/private expert panel to develop a basic standard set of questions about any medication and educate consumers to ask these questions of their physicians, nurses and pharmacists. These standard questions should be validated by consumer focus groups including consumers with limited literacy and limited English proficiency. Public Health messages and patient education programs should disseminate the information. Educate health professionals through their professional associations and institutions to respond clearly to these basic safe medication questions.
  - The Center for Medicare and Medicaid Services (CMS), as it begins to implement the new Medicare prescription drug program, should track the utilization of prescription drugs, the potential for adverse events, the source of purchase of the drug, the frequency of drug substitutions/changes, the results of appeals processes, the availability and accuracy of patient education materials (in multiple languages), the utilization of pharmacy counseling practices to improve patient understanding. This research should be available to health care providers to improve safe prescribing practices and lead to better health outcomes.
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- The number of minority students going into health professions should be increased through public/private partnerships of government, grants, and outreach to these communities.
  - Training and certification programs for interpreters should be developed and these health professionals should be recognized as an essential part of the health care team, and payment should be provided for their services.
  - The Center for Medicare and Medicaid Services and the Agency for Healthcare Research and Quality should support research to identify and evaluate successful practices that ensure patient understanding and eliminate health disparities.
  - All health care providers and third party payors should commit themselves to improving health outcomes, ensuring patient understanding, and eliminating health disparities; all federal agencies regulating and studying the health care system should also so commit themselves and agree to report annually on the progress their agencies and programs are making to achieve this goal.

## Mini-conference on Health Literacy and Health Disparities Report Summary and Recommendations

### **Planning Committee**

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**Joanne Schwartzberg, MD**  
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### **Panel 1 Improving Communications for Better Understanding**

**Toni Cordell**  
Patient Advocate  
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### **Panel 2 Patient Safety and Drug Benefit: Reducing the Risk of Medication Errors**

**David Clark, RPh, MBA**  
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**Terry Davis, PhD**  
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### **Panel 3 Incentives to Improve Quality through Patient Centered Primary Care**

**Darren DeWalt, MD, MPH**  
Assistant Professor of Medicine  
Division of General Internal Medicine

**Toni Flowers, RN**  
("Mary Antonette Flowers")  
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### **Keynote**

**David W. Baker, MD, MPH**  
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